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ABSTRACT

This report of a consensus conference on pediatric rheumatology deals with the complex nature of rheumatological conditions of children, which require diagnostic, therapeutic, and follow-up services for comprehensive care and demand the cooperation of medical, health, education, mental health, and social service professionals. Conference recommendations are presented in the areas of: networking; research; team care financing; community-based family-centered care; legislative advocacy; data collection and database development; and training for physicians, allied health professionals, and patients. The report includes a form for collecting data about pediatric rheumatology patients for a computerized database; and guidelines for pediatric rheumatology fellowship programs, prepared by Deborah Welt Kredich and approved by the Executive Council of the Pediatric Rheumatology Section of the American Academy of Pediatrics. Closing comments are provided by Susan Hurwitch and Frank Donivan. (JDD)

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Future Directions of Pediatric Rheumatology:

A Consensus Conference

January 23-25, 1988
Arlington, Virginia

Patience White, Editor

EC 231185

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Children's *Faculty Associates*
Child *Ventures*

December 21, 1989

Dear Colleague,

This report is the product of a landmark meeting on Pediatric Rheumatology. Over 150 participants representing 49 academic institutions, foundations and agencies, as well as members of multiple comprehensive health care teams for children with Rheumatic disease. These teams included parents, physicians, nurses, social workers, occupational and physical therapists, nutritionists, vocational counselors, psychologists, office managers from across the United States. The document represents diverse view points and offers insightful information on several pertinent issues facing all those involved in the care of children with Rheumatic disease.

This meeting was made possible by the generous support of Dr. Merle McPherson, Director, Division of Services for Children with Special Health Needs, Bureau of Maternal and Child Health. I would also like to thank my staff who made this meeting possible.

Sincerely,

Patience H. White, M.D.
Program Chairman
Future Directions in Pediatric Rheumatology:
A Consensus Conference

PHW/pal

Department of Pediatrics
The George Washington University
Medical Center

INTRODUCTION

The Division of Services for Children with Special Health Needs, Office of Maternal and Child Health (OMCH) is pleased to support the consensus conference and followup activities entitled "Future Directions in Pediatric Rheumatology." This Office had long supported services for children with pediatric rheumatology through funding of regional pediatric rheumatology and cooperative efforts with the National Arthritis Foundation, the American Juvenile Arthritis Organization and the American Academy of Pediatrics.

It is the goal of the OMCH to create a national agenda to improve the lives of disabled and chronically ill children and their families through the provision of family-centered, community-based, coordinated systems of care. This need for coordinated systems of care cannot be over emphasized. The complex nature of rheumatological conditions of children requires expert diagnostic, therapeutic, and followup services for comprehensive care and demands the cooperation of physicians, health professionals and a wide array of education, mental health and social service providers. Through this consensus conference we continue our goal while focusing on new issues to address the needs of children with this chronic illness and their families.

Merle McPherson, M.D.
Director
Division of Services for Children
with Special Health Needs

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NETWORKING ISSUE SESSION RECOMMENDATIONS

Facilitator: Amy Leong

Recorder: Harry Gewanter, M.D.

Participants: Jan Black - Parent, Phyllis Slutsky, R.N., Lee Elliot - Parent, Susan Hurwitch - Parent, Renee Steinway - Parent, Frank Donivan-Parent, Pat Vondran, R.N., Rochelle Kawlewski, M.S.W., Carolyn Braum, R.N., Margaret Gaumond, M.S.W., Alan Kaell, M.D., Lenore Cover, R.N., Mary Vostrejs, P.T., Sandra Lorenz - Parent, Amy Neil, AJAO, Ramelle Pulitzer - Parent, and Sandy Hartman, R.P.T.

NETWORKING

Networking is an informal but systematic process by which people communicate, share ideas and resources in order to resolve common problems or reach mutual goal. Whether called by that name or not, networking goes on informally among professionals, parents and patients, and the general public. Since pediatric rheumatology is a multidisciplinary field, good networking can overcome a number of barriers imposed by tradition, bureaucracy, limited resources and the information explosion. Further, the need for parent/patient support groups to be aware of and communicate with each other locally and nationally is obvious. All networks need to maintain the principles of: keeping focus, staying in touch, remaining in small, simple, cheap and reciprocating.

Inherent in all our recommendations are the following assumptions:

1. Levels of communication exist between and among patients, parents and professional. All communication will be educationally and culturally sensitive and age specific.

2. Appropriate media channels will be utilized to publicize the benefits and use of these networking opportunities.

3. Educational programs will be developed about the pediatric rheumatic diseases and the existence, availability and use of the various networks. We support the Surgeon General's efforts to facilitate these developments.

4. These networks will ideally provide easy, continuous and immediate availability and accessibility of understandable information.

5. Currently existing networks are to be enhanced and expanded where they exist.

6. Inter-organizational contacts/networks are to be enhanced at all levels (e.G., schools, employers, third-party payors, parents; nonprofit organizations and governmental agencies).

We recommend:

1. ENHANCING INFORMAL NETWORKS

   A. Improve communication opportunities at local, regional and national meetings (e.g., ARA/AHPA, AJAO, AF, etc.) by:

      - distributing lists (names, addresses, phone numbers) of participants among participants.

      - providing formal and informal opportunities for individuals to meet.

   B. Encourage programs that enhance networking such as:

      - support groups, camps, social events and family retreats.

      - professional - patient/parent interactions.

2. ESTABLISHING/ENHANCING PRINT NETWORKS

   A. Centers to develop information packets for patients and their families to include:

      - disease information.

      - resource information (e.g., programs, services, support networks, etc.).

   B. Encourage current newsletter editors to coordinate, publicize and exchange:

      - resource and educational information.

      - articles.

      - publication dates.

   C. Enhance and increase circulation of current national newsletters (e.g., AJAO, CHOP) through:

      - recirculation at a local level.

      - establishment of items for children, teens and

young adults.

D. Establish task forces to develop guidelines to assist the development and maintenance of local newsletters.

E. These goals could be accomplished within a year and coordinated through the AF/AJAO.

3. ESTABLISHING TELEPHONE NETWORKS

A. Encourage centers to formalize currently existing informal telephone networks.

B. Develop conferences- call networking capabilities at a local and national level (e.g., Project Telecare).

C. Establish a task force to:

- research currently successful models and alternative systems (e.g., teleconferencing).

D. The local networks could be established within 1-2 years and the national networks in 2-5 years.

4. ESTABLISHING NATIONWIDE COMPUTER NETWORKS

A. Capable of:

- Regional use,
- Electronic Bulletin Board (general distribution),
- Electronic Mail Distribution (specific target)

B. Provide at least the following information:

- News (Newsletters and items of current interest),
- Support via Questions and Answers,
- Databases (e.g., Research, Educational programs, Organizations Services),

C. Establish a task force to resolve issues of:

- Evaluating existing networks (e.g., MCH and SCAN),
- Funding,
- Accessibility,
- System Management,

- User Training,

D. This should be implemented within the following time frame:

- Year 1: Establish task force and resolve issues
- Year 2: Establish pilot program
- Year 3: Publicize existence and encourage general use

CONCLUSIONS

Currently the networking systems within Pediatric Rheumatology includes:

1. Personal contacts and informal get-togethers (usually in association with professional and/pr parent meetings).
2. In Print (usually personal letters and newsletters).
3. Electronic (usually informal networks via phone).

The opportunity, therefore, exists to expand and enhance these networks and create more formalized networks as a means of accomplishing other objectives. We recommend that a Task Force be identified to investigate the most cost effective methods of networking (e.g., phone, computers, modems, etc.) as a means of implementing the recommendations posed by the other six Issue Sessions. Computer networking systems, such as SCAN and Confer II, can be readily accessed through the use of any type of computer and modem at a reasonable cost. We encourage those who are involved in the implementation phase of the various recommendations to investigate and utilize these possibilities.

RESEARCH ISSUE SESSION RECOMMENDATIONS

Facilitator: Michael Miller, M.D.

Recorder: Michael Rapoff, Ph.D.

Participants: Carol Henderson, R.D., Ann Breedlove, O.T.R., Mannuela Giannini, P.T., Andrew Eichenfeld, M.D., Kathleen O'Neil, M.D., Barry Myones, M.D., Thomas Lehman, M.D., Charles Spencer, M.D., R.K. Chambers, Jean Jackson, M.D., Ilona Szer, M.D., Melanie Bacon, R.N., L.M. Pachman, M.D., David Siegel, M.D., Bob Warren, M.D., Leonard Stein, M.D., Karla Jones, R.N., Marilyn Serafin, Alison Partridge, R.A., Joe Butler, M.D., Lawrence Shulman. M.D.

I. Priorities for funding of basic and clinical research.

Funding is needed for studies involving all disciplines that care for children with rheumatologic illness. The following areas all need funding from a variety of sources, depending on the type of project. Although examples in some of the areas are given, the list is not intended to be exhaustive.

A. Psychological Studies

Examples of research areas including the following:

1. Further work is needed on validation of a health status instrument similar to the Arthritis Impact Measurement Scale and Health Assessment Questionnaire for adults.
2. Studies of adherence to medical and non-medical regimens in children with rheumatic diseases need further study.
3. The psychosocial impact of pediatric rheumatologic diseases needs further investigation.
4. The potential long term toxic effects of immunosuppressive agents in children with rheumatologic illnesses needs to be monitored. Potential effects on their progeny needs to be studies.

B. Nutritional Studies

Evaluation of nutritional status and nutritional intervention in children with juvenile rheumatoid arthritis needs further study.

C. Rehabilitation Studies

1. Studies of the effects of exercise on disease, psychological, and nutritional status need to be extended.
2. Studies are needed addressing adjunctive treatment of pain and disability by cognitive behavioral approaches, including biofeedback, relaxation, and pain behavior management strategies.

D. Definition of Diseases - Clinical Studies

1. Epidemiologic Studies

   Regional and national studies of the incidence of rheumatologic diseases and demographic characteristics of affected families will improve understanding of these diseases. These studies should be done with the help of computerized databases.
2. Immunologic Studies

   A national study of juvenile dermatomyositis should investigate the pre-

3. Use of New Technologies
Studies of the use of new technologies to monitor disease activity will improve the care of children with rheumatologic diseases. The use of Magnetic Resonance Imagining to determine joint disease in children with arthritis is an example of such studies.

E. Definition of Diseases - Molecular Studies
1. The use of animal models to further understanding of etiologic aspects of pediatric rheumatologic illnesses. For instance, the efficacy of various treatments for Kawasaki's Disease could be studied in mice injected with lactobacilli.
2. Molecular studies that will determine whether infectious agents, such as retroviruses, interact with genes to produce juvenile rheumatoid arthritis. Other molecular studies can determine whether unique genetic markers, such as particular HLA molecules, are found in and responsible for disease in children with pediatric rheumatologic illnesses.

F. Intervention
1. Rehabilitation
The efficacy of modalities of treatment offered by physical and occupational therapists in the treatment of juvenile arthritis is an important area of study.
2. Pharmacologic
a. New approaches to treatment of juvenile arthritis, such as the use of cyclosporin or intravenous gamma globulin, should be the focus of multi-center drug studies. These studies should be coordinated with cellular and molecular studies designed to monitor response to treatment.
b. Multi-center trials of the effects of immunosuppressive agents on lupus nephritis in children should be organized.
c. Studies can correlate plasma levels of prednisolone with absorption, metabolism, and efficacy in systemic lupus erythematosus, as well as other illnesses.
d. A study of treatment of dermatomyositis should examine the efficacy of pulse methylprednisolone
3. Health Services Research
There is a need to demonstrate the importance of the team approach to management of children with rheumatologic illnesses. For example, this can be done by studies of case management.

II. <u>Development and use of a centralized database for research.</u>

Computer technology can be used to establish a clinical database on children with rheumatologic diseases, using approaches currently used for monitoring patients with other illnesses. This will be very important in epidemiologic studies, as mentioned above. Additional recommendations include:

A. The use of time oriented database software for research.
B. The merging of currently existing data from the Pediatric Rheumatology Collaborative Study Group into a core database whose results could be disseminated to individual investigators, who could study database subsets using meta-analyses.

III. Funding for research.

Funding for research in Pediatric Rheumatology comes from many sources at federal, state, and local levels, depending in part on the type of research being performed. An increase in collaborative efforts, such as is being done through the recently formed Pediatric Rheumatology Basic Science Group, will improve opportunities to obtain funding. It will be very important to promote increasing collaboration in other areas of research as well. Additional recommendations include:

A. That seed money be made available for more pilot studies, allowing investigators to be competitive for more extensive funding.

B. That Pediatric Departments have at least two Pediatric Rheumatologists in major centers, to allow successful research.

C. The establishment of additional training programs for pediatric rheumatologists in basic science areas, such as the coordinated program between the Children's Hospital National Medical Center and the National Institutes of Health.

IV. Publicizing research results.

The Research Issue session recommends the establishment of a clearinghouse for Pediatric Rheumatology Research. This clearinghouse would obtain information on a regular basis from a subcommittee of the Pediatric Rheumatology section of the American Rheumatism Association on the status of all research areas. A full-time research development coordinator should operate this clearinghouse as part of the American Juvenile Arthritis Organization. The clearinghouse would issue regular progress reports as well as coordinate dissemination of information concerning progress in research to AJAO members, the medical community, and the public.

V. Increase transdisciplinary collaborations.

As mentioned above, there is a need to increase transdisciplinary collaboration, not only to increase funding of research, but also to enhance the objects and results of research in Pediatric Rheumatology. Therefore, the following recommendations are made:

A. Activities of the Pediatric Rheumatology Basic Science Group as well as the information of similar study groups with other research interests should be encouraged. Interaction between these various groups will strengthen research in Pediatric Rheumatology.

B. A transdisciplinary research workshop should be established to meet during the ARA/AHPA annual meeting to encourage communication among various disciplines. Initial form of this workshop will be organized by the Research Subcommittee of the Pediatric Rheumatology Section of the American Rheumatism Association for the 1989 meeting, in conjunction with members of the Pediatric Rheumatology section of the Arthritis Allied Health Profession Association.

TEAM CARE FINANCING ISSUE SESSION RECOMMENDATIONS

Facilitator: James Cassidy, M.D.

Recorder: Ann Holman, ACSW

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TEAM CARE FINANCING

This group approached team care financing by dividing the issue into three sequential parts:

1. Identification and discussion of issues that impede satisfactory team financing.
2. Prioritization of fourteen areas and consolidation into four major issues.
3. Re-examination of these four major issues, which are presented in this report.

A number of global concerns were discussed including:

1. The cost effectiveness or justification for team care is seen as a reality and was not further debated.
2. The team approach is viewed as an essential component of (1) case management at the tertiary level and (2) community resources at the secondary or primary level.
3. The functional characteristics of the health care team: (a) Coordination and triage; (b) Efficiency of use of skills or time; (c) Involvement of child, family, and community agencies; and (d) Advocacy and family psychological support.
4. The identification of traditional impediments to team care: (a) Financing and extramural locations; (b) Long-term commitment; (c) Political, community, geographic and corporate barriers to effective implementation; (d) Intrinsic complexity of the system; and (e) Academic/Research Conflicts in the tertiary center.

Financing has increasingly loomed as the central problem of long-term stability of the concept of team care because of (a) finite and perhaps diminshed resources and (b) multiplicity of providers (or non-provision).

On the other hand, issues that lend support to teams or specific members have been

identified, including their attractiveness to clinics, hospitals and third-party providers.

A review of eight centers showed that the teams that had been assembled were more different than similar. Therefore, approaches to financing need to be flexible, politically sensitive, and perhaps geographically specific. In summary, these teams were quite heterogeneous in composition, and financing, and perhaps in actual operation.

The following areas were singled out as important for consideration but will not be discussed further: (1) The educational role of the team; (2) The legitimate advocacy role of the team; and (3) The unintended impact of the present system of financing and determining family eligibility in creating a two-class system.

The four major areas addressed are:

I. The Fee-for-Service System -

The traditional fee for service approach to billing is not always the most effective one for financing interdisciplinary care of chronically ill children. In our session we shared successes and failures in billing, concluding that "fee for service" generally pays for physician time, often for occupational therapy/physical therapy and nursing time but only rarely pays for other medical services. Imaginative approaches have, however, been successful, allowing some programs to bill for other services, such as for inpatient and outpatient nutrition, social work and counseling. The development of legitimate reimbursable team care programs hopefully will supplant much of this and will be sellable to third-party payors. Until this happens, however, we will need to collaborate in the development of effective computer billing systems which will allow us to track services covered for patients, financial resources available and patient needs. Such systems can also smooth billing for these patients, even enhancing collection?! The D-Base 3+ database program was suggested as a possible one with which to work.

Addressing the approach of billing for the team as a unit we felt criteria would need to be devised and universally accepted as to the scale - comprehensive/extended/limited. The fees, of the appropriate services per patient per visit. An example of billing of services for sequential visits for a given patient would be helpful for and understanding of this approach. If we believe in teams we ought, with education and of understanding, be able to convince others that the team itself is the provider and must be payed for! It is remarkable that new approaches to health care provision and cost containment, have complicated our system further. For instance, prepaid health care programs and HMO's may utilize their own internal resources and consultants and allow only for limited input from outside team care coordinators. There may be limited reimbursement for services especially for problems of chronic illness. Some of the most important functions of a team may go uncompensatee in many of these systems, e.g., nurse coordination. There is no standard approach that is evident on the national scene. Services that are reimbursed are highly variable from State to State, and even from county to county within a State.

II. Priority Issue: State Resources And Medicaid Complexity

The following issues were identified with reference to both Medicaid and state Title V children's medical services:

- poor understanding of state plans and therefore poor utilization of full resource potential
- administrative complexity of state plans with slow and incomplete reimbursement
- some rheumatologic conditions are not covered, others are only partially covered. Pediatric Rheumatologists are not always recognized as specialists, nor is team care generally reimbursed.

The Committee, therefore, makes the following recommendations:

- explore individual state plans for resource potential through health policy authorities.
- bring reimbursement problems to the attention of state Medicaid and state Title V authorities.
- advocate long-term illness coverage for children with special health care needs including rheumatic disease.
- negotiate packages to pay for team care where partial reimbursement exists in state plans.

III. Team Specificity/Composition/Coordination

One major area of concern regarding team care financing is the design of a cost effective health care delivery approach.

Experience and utilization of services have demonstrated the need for an interdisciplinary pediatric rheumatology team to provide a coordinated and comprehensive continuum of conscientious care. This care is sensitive to the interdependent needs of the patient and family, the professional care-givers, and the communities in which their care occurs. The functions of clinical research and education are also served by the team.

Essential in providing a comprehensive approach is the need for a case manager to be designated by the interdisciplinary team based on individual treatment needs. The care program is optimally organized on three tiers:

Case finding occurs at the primary level. Diagnostic and initial therapeutic efforts can be carried out effectively in the community by professionals working at the generic chronic disease level with some special skills and interest in the rheumatic diseases and coordinated by a community-based case manager. The tertiary care facility remains in a consultative and definitive role (re: diagnosis and care) and provides not only guidelines for activities at the secondary level but also facilitates ongoing care of the complicated or difficult case.

The definition of tertiary and secondary levels will depend upon the specific geographic location of the coordinating team. Too often the tertiary team has been identified as

that at the University or Medical School level. It may indeed be community based in the larger urban areas or in States that have only a single metropolitan area.

Composition

Tertiary

A. Pediatric Rheumatologist
B. Clinical Nurse Specialist
C. SW
D. PT/OT
E. Orth
F. Ophthy
G. Nutritionist
H. Consultative Services
I. Parent and Child

Secondary

A. Medical Personnel
   1. Pediatric Rheumatologist
   2. Pediatrician
B. Nursing
C. Community Services
D. Parent and Child

Primary

A. Pediatrician/Family Physician
B. School
C. Parent and Child

Secondary teams are usually identified at the community level. They may indeed be located much more specifically within urban developments that have a high frequency of the generic problems that are being addressed. Indeed in large urban areas, such a location of the team may be the only operational model that will meet with success in large residential developments.
The insertion of the HMO into the planning process complicates the geographic location of these resources even further. It is our fear that the HMO's will assume the functions of team management without adequate input from the overall planning process.

The concept of team membership is not a static one or one that can be absolutely predicted in every location. There indeed may be more than one case manager; in all cases the child if old enough and the family if capable enough must be fulfilling at least some role of the case manager.

IV. Accountability and Authority Issues

The administrative structure of the institution has a significant impact on the financing of the health care team. In most institutions each team member is accountable only to the parent department. The team has limited authority with respect to employment issues, duplication or deficiency of services, funding, reimbursable services.

Thus, institutional barriers to an efficient, rational construct for the team loom large in future discussions. These agencies, private third-party carriers, or community agencies that have been placed in competition with each other. It is our judgment that the success of community based coordinated care will in large part depend upon the breaking down of irrational barriers and the implimentation construction of flexible approaches to coordination of the delivery of chronic care.

We therefore recommend a restructuring of the traditional department/discipline organization of health care institutions, so as to facilitate the teams' delivery of comprehensive care. There needs to be some accountability of team members to the team. Revenues generated by team members should be in part directed to the team so as to achieve this accountability. There should be direct representation at an administrative level of the health care team. The time spent in the coordination of the complex health care of patients should be reimbursable with funds in part retrieved to the team.

CONCLUSION

We believe the means are now at hand to positively modify aspects of the team care system and its financial support in order to ensure uniformly available, excellent health

care for all children with special health care needs: family-centered, community-based and coordinated care.

Major areas of focus for change will involve:

1. New federal and state legislation to ensure that no child is without comprehensive, long-term care.

2. Simplification of financial eligibility rules (or their elimination) to reduce a complex, arcane set of innumerable programs to a plan that all can be understood and implemented.

3. Foster communmity inter-agency cooperation at the local level and networking among patients and their families.

4. Careful restructuring of departmental, clinical, hospital and other tertiary barriers in order to facilitate team action as a committed unit.

5. Finally, universal acceptance of the need to provide support for the concept of team care is a reimbursable service for third-party payors.

The American community owes itself the definition and determination of a level of optimal care and the mobilization of resources to enable these plans. The level of care suggested in this summary is unlikely to be fiscally self-sufficient currently: therefore, strongly committed support from the broad national community will be necessary whether through taxation, private, or charitable sources.

Patient	Team Member	Traditional	Non-traditional or Team Package
	MD		
Private insurance	Nurse	- physician time - can bill for nurse pract	Comprehensive Extended
Medicaid	OT	- (limited #)	Limited
BCCS/Children's Services	PT	- (limited #)	
HMO	SW	- can bill for counseling - can bill for psych	
No coverage	Nutritionist	(particularly inpt)	
	Secy		
	Consultants MD		
	Other Consultants		
	MD		
	Personnel	rare	
			Comprehensive Extended Limited

COMMUNITY BASED FAMILY CENTERED CARE

Facilitator: Helen Emery, M.D.

Recorder: Cathy Pacyna, M.S.W.

Participants: Sallie Page-Goertz, R.N., Edith Shear, M.S.W., Mary Gillman, M.S.W., Patty Retting, R.N., cathy Chronic, O.T.R., Valerie Rhodes, M.P.H., Nicholas Patrone, M.D., Mary Myers, O.T.R., Donna DeNapoli, M.S.W., Judy Stebulis, M.S., Laurie Ehner, R.N., Susan Sproule, R.N., Steven Tippett, P.T., Elizabeth Stoff, M.Ed., Herbert Sandvik, A.F., Peggy Schesinger, M.D., Marsha Sullivan, Stephen Derbes, M.D., Mary Wood, R.N., Charlotte Shield, R.N.

INTRODUCTION:

In developing the recommendations presented in this statement, our group used the following approach:

1) defined the components of family centered community based care applicable to children with rheumatic diseases
2) identified problems which may prevent the delivery of this model of care
3) made recommendations which can be applied in the pediatric rheumatology setting to improve family centered community based care.

1) DEFINITION:

The components of family based care are:

a) a commitment to helping families manage their child's care rather than having the system manage them. This implies sharing of decision-making responsibilities between families and professionals.
b) an assessment of the family strengths, values, resources and vulnerable areas should be incorporated into plans for care, recognizing that these may change and require periodic review.
c) information is fundamental to effective family centered care - about the disease process, its management, the resources available, and the child and family's rights and how to obtain them.

2) PROBLEMS OBSTRUCTING FAMILY CENTERED COMMUNITY BASED CARE

Many issues arise which make delivery of an ideal care model difficult in a group of relatively uncommon diseases which may fluctuate in severity and about which there is still a great deal of both public and professional ignorance. These include:

a) delay in diagnosis and inappropriate care because of inadequate professional education in pediatric rheumatology
b) geographic inaccessibility to specialized medical resources, which are generally located in tertiary medical centers
c) lack of appropriate skilled local resources such as physical and occupational therapy to provide ongoing care

d) educational systems which often do not recognize the special needs of children need of children with rheumatic diseases.

e) financial stresses such as difficulty qualifying for insurance coverage because of pre-existing illness exclusions, incomplete coverage, H.M.O. restrictions, or failure to qualify for state programs for crippled children because of diagnostic or financial limitations

f) unfamiliarity of parents with the concept of comprehensive care teams and their potential involvement in care plans

g) lack of comprehensive care teams

h) sense of isolation of both children and families

3) RECOMMENDATIONS

We have developed the following recommendations to try to remedy the deficiencies listed in the previous section.

a) delay in diagnosis and inappropriate care:

Greater emphasis on education at all levels, both for professionals (medical students, residents and practicing physicians as well as for allied health personnel) and for the lay community is required. M.C.H., through its rheumatology centers, has already begun this effort. However, expansion of these programs, and involvement of other professional organizations such as the American Rheumatism Association, the Academy of Pediatrics and the Arthritis Foundation will facilitate enhancing the basic right of children and families - that of a timely, correct diagnosis and quality care. Crippled Children's services can develop "standards of care" for pediatric rheumatic diseases and support centers which meet their criteria.

b) geographic inaccessibility to specialized resources:

Outreach services from existing pediatric rheumatology programs to areas which are distant from tertiary centers can decrease the time and expense required for families to reach needed care have been developed under M.C.H. auspices. These models should be replicated. Channels which facilitate collaboration between local and referral personnel should be established and maintained, recognizing that complex cases may still need referral to the tertiary center.

c) lack of skilled local resources:

Local health professionals should be trained to provide expert care using a coordinated approach, using the resources of a tertiary center for consulting and referral purposes.

d) Unresponsive educational systems:

Parents need to understand their child's rights in schools, including the I.E.P. process, obligations for provision of special services such as physical and occupational therapy, and accessible classrooms. Assistance with negotiating this process and appeals when necessary should be available. Vocational counselling should be initiated early in adolescence, taking into account the special needs of children with rheumatic diseases, using specially trained personnel.

e) financial stresses

Many families face enormous financial problems because of their child's chronic illness. Every family should have access to financial counselling which explores all avenues of potential support, including private insurance as well as state funds for crippled children. Special problems are insurance as well as state funds for crippled children. Special problems are often encountered by members of pre-paid health plans, which may not have appropriate specialists but are reluctant to refer outside their own system. Parents may/should be encouraged to develop advocacy skills to ensure their child receives appropriate services. Families should be aware of the financial implications of changing employment and possible loss of benefits, and be active in efforts to expand coverage for their chronically ill child. In spite of best efforts, there are often major costs born by families.

f. unfamiliarity with comprehensive care concepts

i) When a child and family first interacts with the child's care team, they should receive advance information about what to expect e.g. time commitments, and who they will meet.

ii) Every family should have information about who will be involved in their child's care and their roles.

iii) A care coordinator should be designated to act as a "point person" in interfacing with the family in meeting their child's needs.

iv) Every child should have a goal oriented care plan, developed with ther family, including issues identified as important by them, and updated periodically, e.g., every six months. This can be in a checklist form and tracked on a clinic flow sheet.

v) Consideration should be given to family convenience where possible, e.g., scheduling appointments on the same day.

vi) Families must have access to information on their child's illness and its management so that they can be active participants in decisions about their care, and open communication encouraged.

g) lack of comprehensive care teams

Families should have access to teams of professionals who can meet the needs of their child, siblings and parents. The core team should include a pediatric rheumatologist, nurse, social worker, and physical and occupational therapists. Other professionals may be needed, such as nutritionists, psychologist, and other medical specialists. These teams should interact with school personnel. Where possible, Crippled Children's services should help families identify and coordinate with community resources.

h) sense of isolation

Peer support can be created using a number of resources. Parent groups, under the auspices of the American Juvenile Arthritis Organization and the Arthritis Foundation. Training of parent counselors, newsletters, camps, family oriented activities and even clinic waiting times can be useful.

Overall, families should feel in control of the care they receive without feeling overwhelmed. This implies willingness on the part of the health care team to relinquish some of their traditional roles, to work with families in developing assertiveness and advocacy skills, and to be sensitive to the variations in the state of the family with changing circumstances.

However, we must also recognize that not all families are responsive to this model of care. This should not be misconstrued as failure of the model, but that a different form of care, still focused on the needs of the child and family, but with the health care professionals taking a more directive role until the family can assume more responsibility. The team should not be judgemental over issues such as noncompliance, but still offer opportunities for dialogue. The concept of the team providing a "safety net" for a vulnerable family is valid.

LEGISLATIVE ISSUE SESSION RECOMMENDATIONS

Facilitator: Rick Klonoski, Ph.D.

Recorders: Linda Wetherbee, AF
Jon Hurwitch

Participants: Raquel Hicks, M.D., Vince Londino, M.D., Darlene Muir - Parent, Elaine Woody - Parent, Amy Sharples, R.N., Maggie Lee, M.S.W., Helen Hyler, Mary Long, Roger Hollister, M.D., Linda Dutton - Parent, Al Moseke - Parent, Rob Nickeson, Jr., M.D., and Mark Garson, M.S.W.

INTRODUCTION

Our workshop on legislative issues for future directions in pediatric rheumatology attempted to reach consensus to answers on the following three questions:

1. For which issues should the pediatric rheumatology community engage in legislative advocacy?

2. Who should be the legislative advocate on these issues?

3. What mechanisms should be used in this advocacy effort?

I. ISSUE AREAS AND GOALS

Both federal and state issues were identified. Issue areas and legislative goals are listed below. The highest priority areas of both federal and state goals are starred (*).

A. Federal

1. Educational Services

* Goal: Obtain clarification of the definition of health impairment under PL 94-142, so that children with rheumatic disease are clearly included under the services of the legislation.

2. Research funding issues

* Goal: Obtain language in the NIAMS authorization bill requiring the development of a pediatric rheumatology program within the institute.

Goal: Establish that one of the three NIAMS SCORS for rheumatoid arthritis be specifically for JRA.

Goal: Obtain optimal appropriation for NIAMS.

3. Pediatric Rheumatology Program Funding

*Goal: Obtain optimal appropriation for Maternal and Child Health (both discretionary funds which remain at federal level and block grant funds which go to states).

4. Health Care Financing

*Goal: Mandate federal standards for prepaid (HMO-type) plans to require that these plans provide access to specialty care.

Goal: Examine COBRA legislation to locate and close loopholes regarding health insurance availability and adequacy.

Goal: Find the best strategy to address uninsured population (for example, the development of high risk insurance pool plans).

B. State

1. Research Funding Issues

*Goal: In each state, promote the development of an arthritis plan, which must address pediatric research.

2. Pediatric Rheumatology Program Funding

Goal: Examine state MCH block grant language. Mandate the inclusion of childhood rheumatic diseases in those block grants which list disease categories.

3. Health Care Financing

*Goal: Mandate state legislation for prepaid (HMO-type) plans to require that these plans provide access to specialty medical care.

*Goal: Develop model legislation to be implemented in all states to provide optimal Title V program services.

Goal: Find the best strategy to address uninsured population (for example, the development of high risk insurance pool programs).

Goal: Prevent states from restricting specific medications (i.e., NSAIDS) from their medicaid formularies.

II. WHO SHOULD BE THE LEGISLATIVE ADVOCATE ON THE IDENTIFIED ISSUES?

We identified a number of groups which had an interest in or ability to provide advocacy on these issues. We identified a lead role, supportive roles, and enabling roles in the effort. We also recognized that advocacy is issue-driven, and that the roles may vary, depending on the issue.

A. Lead Role

AJAO, through the Arthritis Foundation's government affairs initiatives, should generally take the lead in advocacy efforts.

1. Foundation maintains ongoing, strong legislative advocacy efforts at the federal and state level.

2. The Foundation represents people with arthritis and AJAO is the arm within the Foundation which is concerned specifically with children, therefore these groups should take the lead in advocacy efforts.

B. Supporting Roles

The American Academy of Pediatrics - Rheumatology Section, The American Rheumatology Association - Pediatric Council, and Pediatric Rheumatology Centers all have a role to play in the effort. They provide expertise and human resources, which can be mobilized.

1. AAP is child focused, not disease specific, has political clout, and is concerned with broad health and safety issues.

2. ARA is disease specific but not child-focused, and is a relative new comer to the legislative arena.

3. Pediatric Rheumatology Centers can function as the focal point of the professional community at the state and local level.

C. Enabling Roles

Other bodies have an enabling role even though they have limitations on the type of advocacy activities they can engage in:

1. MCH and CCS directors: While these individuals cannot do legislative advocacy, their support and/or encouragement is helpful in state/local activity.

2. Individual federal and state legislators and key staff members: These individuals provide contacts to help with legislative advocacy efforts

III. WHAT MECHANISMS SHOULD BE USED IN THIS ADVOCACY EFFORT?

A number of mechanisms were identified to facilitate the legislative advisory effort.

A. Influence on and membership on major federal and state advocacy and policy making boards:

1. Federal - examples:

National Arthritis Advisory Board
NIAMS Advisory Council/Committee
FDA
- Arthritis Advisory Committee
- Orphan Drug Commission

National Science Board
Institute of Medicine

2. State - example:

Governors Arthritis Advisory Board

B. Influence on Executive Level Policy Makers, State and Federal

1. Federal - examples:

Education Department	- Madelyn Will
NIAMS	- Larry Shulman, M.D.
MCH	- Merle McPherson, M.D.
Surgeon General	- Everett Koop, M.D.

2. State - examples:

Education Department
Health Department
Vocational Rehabilitation Department
Others

C. Educate Legislators About Childhood Rheumatic Diseases:

1. send information (i.e., newsletters) NOTE: The Arthritis Foundation was encouraged to develop an "advocacy alert" type system so that individuals have specific information to give their legislators, with instructions on how and when to act.

2. brief in person

3. invite to serve on boards and committees

4. invite to observe/attend AJAO Conference, operation of pediatric rheumatology center

D. Coalition Building

1. Join existing coalitions on broad health/advocacy issues.

2. Establish coalitions on specific pediatric rheumatology issues.

3. Examples of organizations to network with:
Association for the Care of Children's Health
Children's Defense Fund
Parent-to-Parent Groups
Parent Training Centers
Protection and Advocacy Agencies
Disease Groups (Hemophilia, Lupus, Scleroderma, and Diabetes)
Ambulatory Pediatric Association
Easter Seals Society
Arthritis Health Professions Association

IV. SUMMARY

All of the initiatives above can benefit from immediate action, middle range actions, and long range actions. For example, you can

Short Range

- Ask to be put on your AF chapter Government Affairs committee
- Write a letter to your state health department inquiring if there is a state arthritis advisory board
- Write a letter to your legislator informing him/her of the importance of children's health issues

Middle Range

- Investigate coalitions in your community
- Educate your legislator regarding state and federal 1989 appropriations regarding pediatric rheumatology needs, particularly the inclusion of a pediatric rheumatology in the language of the NIAMS reauthorization bill.

Long Range

- Maintain volunteer involvement in all facets of legislative agenda.

DATABASE ISSUE SESSION RECOMMENDATIONS

Facilitator: Daniel Lovell, M.D., M.P.H.

Recorder: Randy Curtis

Participants: Carol Lindsley, M.D., Ed Giannini, Ph.D., Marc C. Hochberg, M.D., Carolyn Anderson, M.D., Harold O'Flaherty, Raymond Patridge, M.D. Bethany Scott, P.T., Carolyn Yancey, M.D., Judy Ann Olson, R.D., Patricia Wells, R.N., Caroline Ross, Sc.D., Susan Hoch, M.D., J. Kenneth Herd, M.D., Lawrence Zemel, M.D., Suzanne Peterson, A.F., Gail McIlwain-Simpson, R.N., Patience H. White, M.D., Maureen Adler.

THE DATABASE ISSUE SESSION MAKES RECOMMENDATIONS IN 6 AREAS:

1. Priority of Issues:

   a. Primary
   - collection of basic demographic, functional, school services, school/work impact data to use for advocacy efforts.
   - utilize attached one page form to develop database capabilities of pediatric rheumatology community and method of data collection/analysis/dispersal.
   - development of computer program which will allow easy access to actual computerized data by all collaborators.

   b. Secondary
   - following development of data base network, study in interested PRC's of medical expenses of rheumatic diseases utilizing mail-out form to determine medical services utilized during a six month period.
   - development of more sophisticated data bases for research questions.

2. Data Base Forms:

   a. Draft of Primary Form Attached

   b. Attached Form Completion
   - majority of form to be completed by patient/parent
   - minimal data to be completed by staff of PRC

   c. Patient Confidentiality
   - patient name to be entered by family at top of form
   - Patient ID Code to be entered as follows:

(New England Method)
First three letters of last name
First two letters of first name
Date of Birth
Example: Randy Curtis B.D. 6/24/54 = CURRA062454

- Patient name to be obscured on form prior to release

d. A pilot project to field test the attached draft data collection form is in progress at 4 pediatric rheumatology centers. The form is being completed independently by the patient/parent and compared to the responses of health care providers who complete the data collection form by a combination of patient interview and chart review. Data will be analyzed for completeness and correlation of responses.

e. Spanish translation of final form will be completed and made available.

3. Data Collection Plan

a. During a designated one month period in 1988, all PRs will make an effort to get the attached data base completed on as many patients followed in PRC as possible.

Suggested approach - form to be completed in clinic on all patients seen in clinic during the month.

- mail form to all patients ever seen but not scheduled to be seen in clinic during this period. After 2 weeks, mail reminder postcard to nonresponders. After four weeks send second, more appealing, cover letter and form.

b. Completed Data Forms to be sent to Dan Lovell, M.D., M.P.H., Cincinnati, OH for data entry and analysis. Data to be entered into IBM PC utilizing Medlog Software. Decision based on computer system which allows greater access to data by all members of Pediatric Rheumatology community generating ASCII files.

4. "Pediatric Rheumatology Data Base Research Coordinating Committee"

a. The ongoing coordination and direction of data base efforts to be assigned to above committee.

b. Roles
- development of new data bases
- coordination of existent data bases
- obtain external funding for data bank efforts
- coord. publication and circulation of results
- development of PR database directory

c. Members- 5 members of PR community with ongoing interest in clinical data bank issues and

- PRCSG data base coordinator
- PRBSG representative
- CDC representative
- MCH representative
- Parent
- Data base coordinator/expert from other large clinical data base

5. Hardware/Software

a. Future efforts in PR data bank will occur on personal computers.
b. Develop scannable data collection form which would allow for direct entry of data into computer from machine decoding of form.
c. Seek funding to allow development of software specific for PR data bank efforts (similar to Hemophilia Project)

6. Use of Data Generated by Attached Data Collection Form Beyond Pediatric Rheumatology Community

a. Provide data to MCH for advocacy efforts with federal legislators
b. Provide data to Government Affairs Committee of Arthritis Foundation to lobby at federal level
c. Provide data to advocacy committee and general members of American Juvenile Arthritis Organization

PEDIATRIC RHEUMATOLOGY QUESTIONNAIRE CENTER NAME _____

PARENTS TO COMPLETE SECTIONS I AND II

I. CURRENT INFORMATION - ALL QUESTIONS IN THIS SECTION RELATE TO THE CURRENT TIME

1. Patient's name _____
2. Sex _____
3. Race/Ethnic Group _____(W)hite, (B)lack, (H)ispanic, (A)sian, (N)ative American, (O)ther
4. Birthdate: ___/___/___ mon day year
5. Current zip code _____
6. Insurance type: Private ____ HMO ____ Medicare/aid ____ Crippled Children's ____ None ____
7. Family income level: less than $10,000 ____ $10-20,000 ____ $20-30,000 ____ $30-40,000 ____ $40-50,000 ____ over $50,000 ____
8. Number of School/Work days missed by patient in last 2 months related to rheumatic disease (remember to add clinic visits and part days missed) ____
9. Number of School/Work days missed by parent (count both parents if both work or go to school) in last 2 months related to rheumatic disease ____
10. Number of days in hospital in last 2 monthsdue to rheumatic disease ____
11. Patient's Current School Level: Grade 1-12 (please write in grade level) ____ Preschool ____ Kindergarten ____ High School Grad ____
12. Currently attending school (grades 1-12): Full Day ____ Part Day ____ Homebound ____
13. If patient is 18 years or older and not in H.S.: College currently ____ College grad ____ Work ____ Unemployed ____
14. Educational level of parent: Not H.S. grade ____ H.S. grad ____ Some college but not degree ____ Bachelor's degree ____ Master's degree ____ Doctor's degree ____
15. Does rheumatic disease limit patient's choice of activities: Never __ Sometimes __ Often __ Always __
16. Does rheumatic disease limit family choice of activities: Never __ Sometimes __ Often __ Always __
17. Does patient use a cane, crutch, wheelchair: Never __ Sometimes __ Often __ Always __
18. Current functional level (please check one):
    ____ unable to do any ordinary play or attend any school except homebound
    ____ can do some ordinary play but needs extra rest, if school age
    ____ needs special school or teaching, part days or long periods of absence.
    ____ can do ordinary play and school but limited in sports or extra-curricular activities.
    ____ not limited in any activity.
19. Adult caretakers in household: Mother____Father____Stepparent____Others____
20. Number of sibs ____

II. PAST INFORMATIONALL QUESTIONS IN THIS SECTION RELATE TO PREVIOUS TIMES (IF CAN'T REMEMBER ACCURATELY, LEAVE BLANK)

21. Date of onset of symptoms of rheumatic disease ___/___ (mon yr)

22. Date of initial doctor visit for rheumatic symptoms ___/___ (mon yr)

23. Zip code at onset of symptoms ____

24. Medical Providers seen: Fill in C if provider based in your community, P if based at rheumatology clinic, B if providers in both places, or if rheumatology clinic is in your community

	Providers seen for rheumatic disease symptoms prior to first rheumatology clinic appointment	Providers seen since last rheum. clinic appointment or as result of referral to rheumatology clinic
Pediatrician		
Orthopedics		
Family Practice		
Ophthalmology		
Adult Rheumatologist		
Pediatric Rheumatologist		
Nurse Clinician		
OT		
PT		
Social Worker		
Nutritionist		
Dentist		
Vocational Rehabilitation		

III. TO BE COMPLETED BY CLINICAL PERSONNEL

25. Patient ID Code _____
Diagnosis Codes:

(1) Pauci JRA
(2) Poly JRA
(3) Systemic JRA
(4) Probable JRA
(5) SLE
(6) Dermatomyositis
(7) ARF
(8) Kawasaki Disease
(9) HSP
(10) Lyme Disease
(11) Scleroderma
(12) MCTD
(13) Juvenile Ankylosing Spondylitis
(14) Post-strep reactive arthritis
(15) Other reactive arthritis
(16) Vasculitis
(17) Reflex Sympathetic Dystrophy
(18) Septic Arthritis
(19) Osteomyelitis
(20) Malignancy
(21) R/O CTD
(22) No CTD
(23) Other

26. Referral Diagnosis Code _____
27. Rheumatology Clinic Diagnosis Code _____

28. Major unrelated chronic disease in patient: No ____ Yes ____
    If yes, write in diagnosis _____
29. Date of diagnosis of rheumatic disease ____/____
    mon year
30. Date first seen at pediatric rheumatology clinic ____/____
    mon year

TRAINING ISSUE SESSION RECOMMENDATIONS

Facilitator: Deborah Kredich, M.D.

Recorder: Lynn Colby, LPT, M.S.

Participants: Susan Wright, O.T.R., Gerri McGirr, O.T., Karyl Barron, M.D., Balu Athreya, M.D., Sue Graff, M.S.P.T., Arlene Cutter, O.T.R., Louise Watts, R.N., M.S.N., Bram Bernstein, M.D., Marie Weafer, R.P.T., Chester Fink, M.D., David Sherry, M.D., Kathy Salmonson, R.N., Susan Hill, O.T., Bernhard H. Singsen, M.D., Bob Lipnick, M.D., Joane Gates, P.T., and Elaine Carmichael, R.P.T.

TRAINING ISSUE SESSION RECOMMENDATIONS

I. Allied Health Professional (AHP) Training

A. Medical doctors should advocate with department heads of Occupational Therapy, Physical Therapy, Social Work, Nutrition and Nursing to stress the importance of these positions within the pediatric rheumatology team. This action will serve to validate the academic importance of these professions and their importance to the pediatric rheumatology health care team.

B. Consider a study to identify the actual need for AHP's in the field of pediatric rheumatology.

1. In what settings are AHP's with pediatric rheumtology training in most demand? (school settings, acute pediatric settings, home health, etc.)

C. Pediatric rheumatology needs to impact the training of AHP's so student candidates are interested prior to graduation.

1. Ask AHP program directors and non-clinical teachers to come to clinics, thereby providing relief-time for team members and increasing the reality base for the directors.

2. Encourage pediatric rheumatologists to be guest lecturers in AHP training; particularly at the undergraduate level.

3. Foster interest in pediatric rheumatology by encouraging undergraduate projects/senior papers to be done in field - our AHP's can serve as resources.

4. Encourage rheumatology AHP's to enthusiastically lobby with students - they are the role models.

5. Establish for the undergraduate a model of an effective team to be emulated and admired. They are exposed to various team models; rheumatology should be the prototype for patients and clinics.

6. Make better use of pediatric rheumatology for AHP undergraduate clinical affiliation.

7. Consider arthritis camps as a possible site for AHP clinical undergraduate training - an opportunity for the AHP student to see the child in a non-clinical environment.

D. Attract the AHP graduates to pediatric rheumatology i.e. recruitment.

1. Offer local conferences (interdisciplinary), for CME credit.

2. Offer AHP fellowship for training in pediatric rheumatology i.e. national conferences.

3. Utilize AHP network to inform schools and journals of job opportunities available, fellowships, etc.

E. Keep AHP's in pediatric rheumatology

1. Enhance the team concept/home base so that job satisfaction outweighs monetary considerations.

2. Encourage growth/advancement of individual careers by fostering clinical research by AHP's--encourage AHP's to seek grants, write papers, etc.

Such grants would produce revenue for
a. Relief time (from clinical duties)
b. Help with data collection and evaluation
c. Training in research design
d. Training in grant writing
e. Sending AHP's to national meetings

3. Encourage collaborative efforts with AHP's from various centers

F. Look for ways to increase billing for team function such as reimbursement for nurses teaching time, social work input, etc. (explore CF, Diabetes mechanisms).

G. A need has been identified for the occurrence of a national metting of pediatric arthritis helth professionals, either in conjunction with the ARA - AHP meeting or with an AJAO gathering. This would be a forum for networking and sharing as well as one in which research projects could be presented and opportunities for collaboration explored.

II. Pediatric Rheumatology Fellowship Recommendations

A. Document "for thought".

B. Discussion points.

1. Duration - 3 years
flexibility of clinical/research split

2. Necessity for longitudinal follow-up of patient cohort even in research years

3. Recognition that learning is a lifetime endeavor i.e. does not end with fellowship; therefore, not all must be taught in a fellowship.

4. Necessity for protected post-fellowship positions i.e. junior faculty, with start-up funds, access to wide range of good basic science mentors and minimal clinical responsibilities.

5. Role of fellow: service vs. teaching

6. Should there be different training programs? All clinical vs. many research vs. equal weight.

7. Need to attract more individuals to pediatric rheumatology i.e. attract medical students with appealing electives, perhaps in combination with orthopedics or sports medicine. Encourage outpatient exposure to pediatric rheumatology clinics for interns. Encourage summer research opportunities for medical students - AF has fellowships

C. 1. Funding - for fellows as well as faculty

- Hospital
- RO's
- Clinical dollars generated
- Private sources

2. Must proceed with faith that creative minds, well trained, will find new avenues of funding as the old dry up.

D. Document the need for pediatric rheumatologists in what type of settings.

III. Patient Training/Education

A. Parents as coordinators of their child's care.

1. Need more consistent and organized methods of helping parents become more knowledgeable about the many aspects (medical, physical, functional, social, nutritional) of their child's care.

2. Possibility of in-depth training through educational activities of AJAO

B. Assist parents in learning how to become advocates for their child or for children with pediatric rheumatology conditions.
1. coordination with schools and special school programs for their child
2. advocates in the legislative process.

Guidelines for Pediatric Rheumatology Fellowship Programs

Deborah Welt Kredich

Approved by Executive Council of Pediatric Rheumatology Section of AAP 5-24-88

Executive Committee, Section on Pediatric Rheumatology, ARA 5-25-88

Final Revision 11-88

Guidelines for Pediatric Rheumatology Training Programs

I. Introduction

Training in pediatric rheumatology should be structured to prepare physicians for academic careers, since it is unlikely that many physicians in this subspecialty would thrive in a non-academic setting. Such a training program must be designed to impart the necessary clinical skills required to take care of pediatric patients with rheumatologic disease, and to provide consultative services for other physicians caring for such patients. Additionally, the trainee must be educated in the other disciplines required of an academician; i.e. learning to be an effective teacher to learners of various levels, learning to design and execute meaningful research in clinical or basic science arenas pertinent to the field of pediatric rheumatology, and learning to report new information generated by such research in peer-reviewed literature. At the end of the training program, the trainee should have the skills necessary to compete for competitive, peer-reviewed funding.

II. Objectives of the Training Program

A. Clinical Skills

The competent pediatric rheumatologist must be able to:

1. Perform a comprehensive rheumatologic history and physical.

2. Formulate a differential diagnosis on the basis of these clinical findings and appropriate lab studies.

3. Provide comprehensive primary care or consultative rheumatologic care to patients with rheumatic diseases.

4. Have in-depth knowledge of pediatric rheumatologic diseases; have in-depth knowledge of pediatrics in general, and be aware of enough of the natural history and long-term follow-up of rheumatic diseases to be able to consult meaningfully on the complex patient with unknown disease.

5. Have an in-depth knowledge of the anatomy and physiology of the musculoskeletal system, pharmacology and side-effects of drugs used in the treatment of rheumatic disease, mechanisms of tissue injury and repair including the immunologic and inflammatory aspects of rheumatic diseases, and knowledge of

the psychologic and behavioral consequences of rheumatic diseases.

6. Have in-depth understanding of the various modalities of therapy in the rheumatic diseases, including drug therapy, appropriate orthopedic consultation and surgical intervention, use of splints, use of physical modalities, knowledge of isometric and isotonic exercise routines, and psychiatric or psychologic intervention.

7. The trainee must be able to perform independently:

a. Aspiration and injection of joints and the interpretation of the analysis of joint fluid.

b. Prescription of physical therapy, occupational therapy, splints, and other therapeutic modalities.

c. Interpretation of various imaging techniques required for the diagnosis and the care of the rheumatology patient.

d. Evaluation for surgical intervention; pre- and post-operative patient management.

e. Interpretation of the various laboratory tests (serologic, immunologic, pathologic, electrophysiologic, etc.) as they relate to rheumatic disorders.

8. Organization and leadership of a comprehensive health care team in the care of the individual patient.

a. Education of the patient, parents, school personnel and other pertinent parties.

b. Prescription of all necessary drugs and monitoring the same.

c. Utilization of the services of all relevant allied health professionals including those in social services, rehabilitation, education and mental health.

B. Teaching Skills

Teaching proficiency must be encouraged and fostered since the trainee will have a major role as teacher to house officers, students, health professionals, and other physicians for the entirety of his/her career.

1. A rheumatology trainee should be able to organize existing information on a disease, a process, or a subject into a cogent talk supported by audiovisual aids, and to be able to present information to (a) lay audiences, (b) medical or health professional students, (c) house staff, (d) a broad medical audience.

2. The trainee should be able to impart knowledge about disease and treatment to parents, children, teachers, etc.

3. The trainee must be able to teach the basics of pediatric rheumatologic physical diagnosis to learners at various stages and in various disciplines (i.e. students in nursing, physical therapy, medicine, PA school, etc.).

C. Research Skills

The trainee should be able to:

1. Critically synthesize current knowledge in a specific clinical or basic science subject relevant to pediatric rheumatology.

2. Formulate a hypothesis, and design and conduct a study to test said hypothesis.

3. Design and conduct experiments requiring collection and analysis of primary data.

4. Evaluate the statistical validity and methodologies of published data.

5. Write and present original work in a forum suitable for publication in a peer-reviewed journal.

6. Develop sufficient expertise in the chosen area of research to be competitive for grant funding after the fellowship.

III. Organization of the Fellowship Program

The American Board of Pediatrics is currently viewing with favor the idea of an application by Pediatric Rheumatology for subspecialty boards. All subspecialty training programs in pediatrics in the 1990's will consist of a minimum of three years of training; therefore the design of pediatric rheumatology programs must conform to this. Since pediatric rheumatology contains a substantial body of knowledge and deals with chronic disease, a longitudinal supervised experience over the course of three years is optimal. Additionally, acquisition of the skills for competent research require at least two full years.

A. Location

The rheumatology training program must be based in a teaching hospital affiliated with an accredited medical school or with a research institute. There must be an accredited three year pediatric training program and access to accredited programs in all traditional specialty and subspecialty clinical disciplines of pediatrics and pediatric surgery.

B. Faculty

The program director must be a recognized pediatric rheumatologist. Ideally, there would be other pediatric rheumatology faculty with diverse skills in clinical and basic science research. Other supportive pediatric and basic science faculty with diverse skills should be involved.

C. Trainees

Trainees should have had three years of accredited pediatric residency or be board eligible. In special instances, where the American Board of Pediatrics is in agreement, a trainee might enter a fellowship with two years of residency; most of these trainees would have had prior Ph.D.'s. Ideally, there would be at least one trainee at each level of the three year program.

D. Duration of Training

As stated above, the training program will be a minimum of three years in duration, with the first year being primarily clinical and the second two years being devoted primarily to research endeavors but encompassing a longitudinal clinical experience as well. Some flexibility in the structure of the second year is desirable.

E. Specific Environment

1. There should be in-patient facilities for the care of acutely ill rheumatology patients.

2. There should be ambulatory facilities with adequate space and staff. The rheumatology faculty should participate in the clinical supervision and teaching in the ambulatory setting. The spectrum of disease must be broad and number of patients sufficient for adequate exposure by the trainee. Scheduling in the second and third years of traineeship should allow the fellow to follow a cohort of patients longitudinally throughout the fellowship.

3. Some clinical exposure to adult rheumatology patients might be obtained. This could be accomplished by having the trainee serve as consult fellow on the adult rheumatology service for 1-2 months of the first (clinical) year. Supervision should be available by adult rheumatology faculty as well as fellows.

4. Facilities must be available for the performance and the interpretation of radiographic and other imaging studies of the musculoskeletal system.

5. Clinical laboratory service must be available, offering the full array of specialized tests used by rheumatologists. It is suggested that the trainee spend time in

the laboratory, familiarizing himself with methodology, limits of tests, etc.

6. Registered physical and occupational therapists must be available to provide consultation and patient education.

7. Orthopedic services must be available to the patients and staff of the rheumatology training program.

8. Regular conferences must be included in the training program:

a. Patient care conferences, with both faculty and trainees participating, are important for education. It is suggested that these last an hour and be held at least once a month. The trainee should present at patient care conferences, with support and input from the various faculty members.

b. A Journal Club should be part of the training program and should occur once a month. In this forum there should be critical review of current literature spanning the clinical as well as the basic and epidemiologic literature pertinent to the subject. The goal of such an experience is to develop systematic habits of acquiring the specialized knowledge essential to serving as a consultant in the area.

c. X-ray conference should be held once a month with competent pediatric radiologist.

d. Pathology should be formally reviewed as needed (every three months - renal biopsies, muscle biopsies, etc.).

F. In general, the program must include:

1. Instruction in the scientific bases of rheumatology:

a. Anatomy, genetics, biochemistry, and physiology of connective tissue disease, bone and muscle.

b. Immunology relevant to pathogenesis of rheumatic disease.

c. Microbiology and infectious diseases as related to rheumatic diseases.

d. Biostatistics.

2. Acquisition of competence in clinical skills listed in IIA.

3. Exposure to a broad clinical spectrum of diagnoses and treatments in both inpatient and outpatient settings:

The trainee must be exposed to a wide variety of patients with connective tissue diseases (JRA, SLE, scleroderma, dermatomyositis, polymyositis, Kawasaki disease, various vasculitides, non-articular rheumatic diseases, systemic diseases with articular manifestations, metabolic diseases of bone, infections of bones and joints, patients both before and after surgery, and neonates with consequences of maternal rheumatic diseases).

4. Knowledge of clinical pharmacology in rheumatic diseases:

a. Training in the use of NSAID's, disease modifying agents, steroids, cytotoxic drugs, and antibiotics.

b. Appreciation of drug side-effects, drug-drug interactions and costs.

c. Observation of controlled therapeutic trials in rheumatic disease.

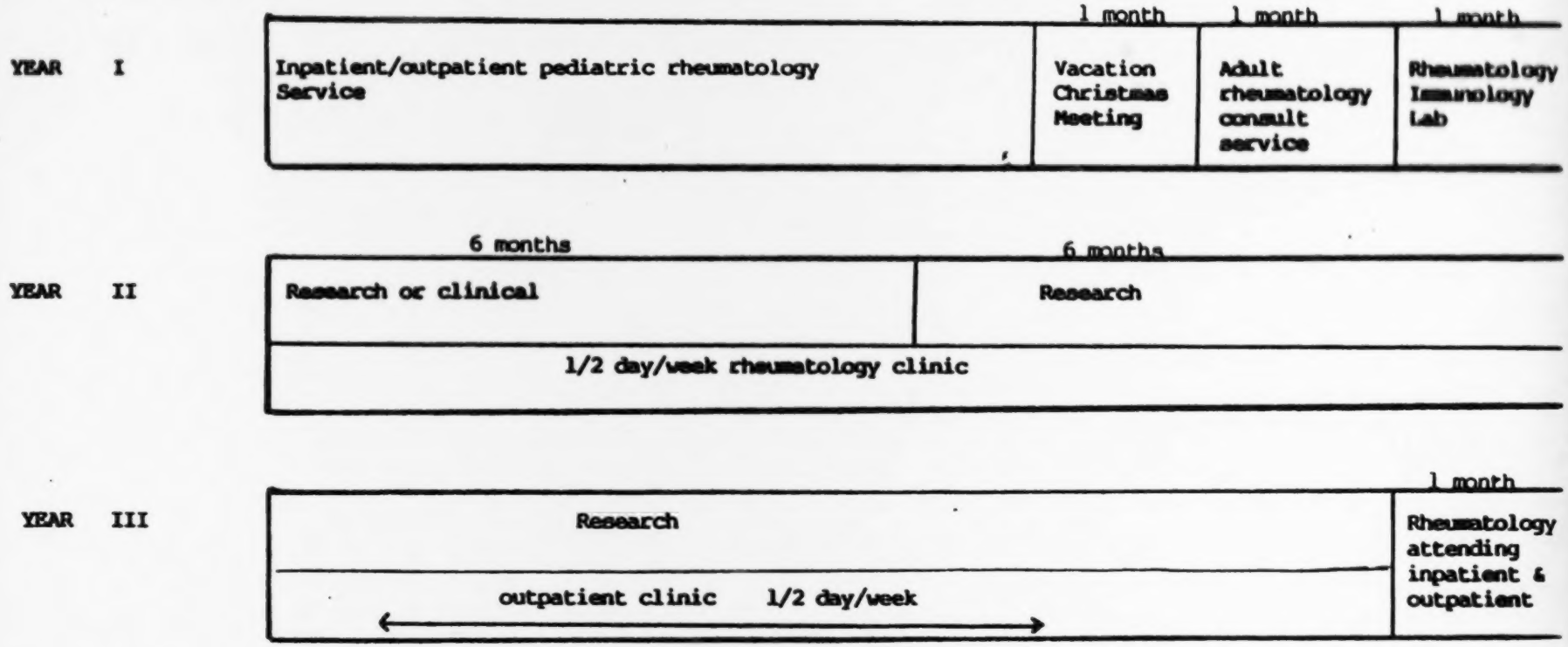
5. Knowledge of physical modalities:

a. Knowledge of the principles of physical and occupational therapy in joint disease, and of the indications for surgery and orthopedic consultation.

b. Understanding of any indications for and interpretations of EMG's, nerve conduction studies, muscle and nerve biopsies.

6. Knowledge and skills in psychosocial aspects of chronic disease, especially the developmental impact.

Sample Pediatric Rheumatology Training Program Schedule



Future Directions of Pediatric Rheumatology:
A Concensus Conference
Closing Comments: Susan Hurwitch

When Dr. White first asked me to deliver the closing comments at this conference, my first instinct was to say "no". I'll be quite honest and tell you that the major reason for that was that I am not very comfortable speaking in front of an audience. However, the more I thought about it I realized that part of the reason I wanted to participate in this conference was that as a parent of a child with arthritis, I recognize the need for my daughter and for all children with rheumatic diseases to have a voice in the issues that surround their illness.

So, with this in mind, I would like to share with you how I come to stand here before you today. Two years ago, my daughter was diagnosed with juvenile rheumatoid arthritis, just weeks before her fifth birthday. Words really cannot express the emotions that were felt by both my husband and I when we learned of her illness. But, when the cloud of confusion settled, I knew that I had to move in a positive direction by becoming involved with other families in an effort to deal with the drastic change in our family life. I must confess that at that point, my motivation was completely self-serving.

But, an interesting thing happened over the course of the past two years. Thanks to the Comprehensive Pediatric Rheumatology Center and the local chapter of the Arthritis Foundation here in Washington, D.C., I was provided with the resources to involve myself with our parents' group and I was able to attend the AJAO conferences in Downingtown, PA. and Long Beach, CA. Through these experiences I met many other families and children with rheumatic diseases and I realized that my involvement had become about something more than just my daughter. It was about the family that not only struggles with their child's illness but how they are going to pay for medical care. It was about the family living in a rural area of the country who is trying to deal with not only their child's pain but with the knowledge that they are isolated from the benefit of quality care. It was about the family who could not find a pediatric rheumatologist in their area because there just aren't enough trained in the specialty. And it was about finding a way to make a difference in the lives and the future of everyone who is touched by the pain of rheumatic disease.

I have told you the reasons for my involvement but I would like to let you know what else I have observed since my daughter was diagnosed with juvenile arthritis. I have seen just how much the health care professionals in the field of pediatric rheumatology really care about the families they treat. I think the number in attendance at this conference is evidence of that. I have also sensed their frustration over the lack of funding for programs like Community Based Family Centered Care, establishment of a database, team care and research.

While health care professionals have been working to ease the burden on families, parents of children with rheumatic diseases are still aware that while the medical needs of the illness may have been met many of the broader issues that will affect their future have not been addressed. This conference has provided the forum to address these needs as defined by parents, professionals and most importantly, caring individuals. We have discussed some very important issues here and we need to be unified in our approach to them.

Every parent has hope and vision for their child's future. For parents of a child with a

rheumatic disease, this hope and vision can become somewhat clouded as they struggle for recognition of the needs of their child's illness. I hope each and everyone of us can come away from this conference with renewed hope and vision for children with rheumatic diseases and more importantly the direction and commitment to giving these children a voice that will be heard and will provide them with the resources to ease their struggle and give them the opportunity to excel to their fullest potential.

Closing Comments From the Perspective of an Involved Parent
by Frank Donivan

On behalf of the 200 thousand children and families involved with juvenile arthritis I would like to thank all of you for participating in this landmark Consensus Conference on Pediatric Rheumatology. The strategies, goals and plans developed this weekend many germinate for some time for eventually they will bear fruit and help achieve our ultimate goal to make life better for all youngsters with rheumatic diseases.

This year the Executive Committee of the American Juvenile Arthritis Organization is evaluating and establishing its strategy for the next five to ten years. As the result of a planning session held last Fall, six committees were formed to develop the strategy for the AJAO. Let me mention a few and see if they sound familiar to you, Research, Advocacy, Medical Education and Training, Economics of Juvenile Arthritis and Evaluating Health Care for Children with Rheumatic Diseases. You obviously recognize the similarity between these and the issue sessions of this conference: Research, Legislative, Training, Financing Team Care and Networking. This is not a chance coincidence. Both the Arthritis Foundation, through the AJAO, and you, the community of pediatric rheumatology health care specialists, have a common interest and goal. Working together we will achieve this goal. Progress may seem slow, but it will come. As my daughter Laura was exercising her hand following reconstructive surgery she complained about the slowness of her progress. I pointed out that if she would work each day to lift her fingers just one millimeter further than the day before, one tiny millimeter, after three weeks she would be able to lift her fingers one whole inch! Progress may be slow -- but we WILL succeed.

Earlier today the rhetorical question was asked "Will the AJAO accept the role as the legislative advocate for pediatric rheumatology?" Without needing to poll the membership I can answer in the affirmative. If you question whether the parents and families are committed to accepting an assertive role -- just watch us!

As a demonstration of how interested we are, let me mention two events which will occur this year. First, is "Arthritis in Prime Time -- A Symposium for Young Adults " which will be held in southern California on Saturday, May 7th. Last year's conference, the first of its kind ever held in the U.S., drew 150 young adults impacted by arthritis. This year we expect 300 to attend. Second is the Fifth Annual AJAO Conference, to be held July 5 to 8 in Chicago. The theme is "Growing Concerns". More than 600 youngsters with arthritis, their parents and health professionals from all over the country will spend four days dealing with the physical, psychological and organizational

issues of arthritis. I am certain that each of you here today will attend this conference.

All of you attending this conference are here because you are leaders. Most of you have organized workshops and conference yourselves and you know that it takes a team effort. But you also know that no project will succeed unless it has a dynamic leader with a vision. In the world of physics we call this a driving force. The force of this consensus conference has been Dr. Patience White. On behalf of my daughter, all children with rheumatic diseases, and the AJAO we all thank you Patience, for your efforts and dedication to organizing and leading this program. The work of Dr. White and her team is yet another demonstration that no goal is unattainable -- if we are determined to succeed.

In a very personal way I want to encourage each of the groups which drew up a plan of action this weekend to follow through and implement the recommendations. Each of us can be part of a larger team and as such can help accomplish a large task. As some of you know, I play a small role in mankind's exploration of the planets of the solar system through my work at Jet Propulsion Laboratory. If our team of 100 members can fly the Voyager spacecraft over three billion miles to the planets of Jupiter, Saturn, Uranus, Neptune and one out into interstellar space then this room full of dedicated individuals and the teams you represent can improve the health care and the lives of children with arthritis and rheumatic diseases.

THERE IS NO ALTERNATIVE -- THE CHILDREN ARE DEPENDING ON US!